‘Getting into it’: people with intellectual disabilities’ experiences and views of Behavioural Activation and Guided Self-Help for depression

Abstract

Background: No studies have explored the acceptability of Behavioural activation and Guided Self-Help interventions for depression with people who have intellectual disabilities.

Method: Twenty five participants were purposively sampled from participants taking part in a trial comparing Behavioural Activation with a Guided Self-Help intervention. A Framework Analysis was used to analyse interviews covering participants’ expectations and views of therapy.

Results: Participants were largely positive about both interventions. However, they identified specific aspects of each intervention which they had found helpful. All participants valued the therapeutic relationship. The participants also had a number of criticisms and suggestions for improving the therapies. A common concern was the time limited nature of the interventions and a wish for longer-term help. Overall, both sets of participants felt the interventions had relevance for their wider lives.

Conclusions: The participants reported having positive engagement with the therapies but expressed a wish for longer-term supportive relationships.

Introduction

There is a dearth of research concerning psychological therapies for people with intellectual disabilities, despite epidemiological studies suggesting that mental health problems are at least as prevalent as in the general population (Cooper, Smiley, Morrison, & Williamson, 2007). There are also a number of factors relating to the particular life circumstances of people with an intellectual disability that might contribute to the development and maintenance of mental health problems. For example, belonging to a stigmatised and socially marginalised group is likely to make people with intellectual disabilities more vulnerable to depression (Jahoda, Dagnan, Jarvie, & Kerr, 2006). This means that while it is crucial to adapt and examine the effectiveness of psychological interventions for mental health problems, it is also important to understand how individuals with intellectual disabilities make sense of these interventions in the relation to their life circumstances and experience.

There is a relatively small literature on the perspectives of people with intellectual disabilities who have received psychological therapies. As part of a study examining process issues underpinning the use of CBT with people who have intellectual disabilities, Pert et al (2013) interviewed 15 participants about their experience of therapy. While the participants appreciated the particular techniques used by the therapists, they were most positive about the 'non-specific' aspects of therapy, including being listened to and respected by the therapist. Some also expressed concerns that any progress made in therapy would be short-lived. Similar views were obtained from 11 participants with intellectual disabilities who took part in group interventions for anger management (MacMahon et al, 2015). These participants highlighted the opportunities for learning and building relationships in a group context. Moreover, the group also allowed the participants to promote more positive identities and to show off their new skills to others in the group. McDonald, Sinason and Hollins (2003) explored the views of nine individuals who had been in a psychodynamic psychotherapy group, either as part of a sex offender or women's group. Whilst many of the findings overlapped with MacMahon et al (2015), participants also reported a number of difficulties with the group format, including an inability to relate to other group members and conflict in the group.

There are limits to the adaptations that can be made to psychological therapies for people with intellectual disabilities. Even adapted CBT makes considerable cognitive and communicative demands on individuals, limiting its use to those with mild to moderate intellectual disabilities (Jahoda, Pert and Stenfert Kroese, 2017). Behavioural activation (BA)

is an established and evidence-based approach to tackling depression which makes fewer cognitive and communicative demands (Dobson et al, 2008; Richards et al, 2016; Jahoda et al, 2015). The underpinning theory of BA is that depression is associated with withdrawal from purposeful and adaptive activities that are linked to positive contingencies. Thus the core of the intervention is an attempt to increase purposeful and personally meaningful activities, with the aim of overcoming the cycle of depressive avoidance. Behavioural activation may be particularly suitable for people with intellectual disabilities, who are often socially marginalised and have little regular purposeful activity in their lives (Abbott & McConkey, 2006). There is little evidence for other established psychological interventions for depression such as CBT self-help approaches using psycho education or problem solving (Merry et al, 2012; Richards et al 2003; Cuijpers et al, 2010), with people who have an intellectual disability. These CBT based sel-help interventions tend to take a very different approach to behavioural activation, with an emphasis on giving people the knowledge, skills and confidence to tackle some of the core symptoms of depression through such means as learning about how to develop a better sleep pattern, understanding the benefits of taking more exercise and finding out how to improve their problem solving skills.

To date no studies have been reported concerning the experiences of people with intellectual disabilities receiving an individual psychological intervention in the context of a randomised controlled trial. Nor has there been research concerning people with intellectual disabilities' experience of behavioural activation or any form of guided self-help intervention. In terms of the broader literature concerning general adults' experience of receiving psychological therapies, there would appear to be commonalities with the views of participants with learning disabilities described above. A study by Finning et al (2017) explored the views of participants taking part in a large non inferiority trial of behavioral activation compared to cognitive behavioural therapy in general adult mental health. They found that both groups of participants receiving both interventions valued the non specific elements of therapy like the therapeutic relationship, whilst also placing value on the specific therapeutic techniques used in each of the interventions. The value of experiential work was emphasized in an Interpretative Phenomenological study of individuals receiving cognitive therapy for social phobia (McManus et al, 2010).

In the current paper, we explore the experiences of adults with intellectual disabilities randomised to one of two psychological interventions for depression; behavioural activation or guided self-help, using a psycho-educational approach. This was a component of a

randomised controlled trial (RCT) whose primary objective was to compare the clinical and cost effectiveness of behavioural activation vs. guided self-help for the treatment of depressive symptoms in adults with intellectual disabilities (Jahoda et al, 2017). Both interventions were adapted to be suitable for adults with mild and moderate intellectual disabilities. Participants were recruited from three centres in Scotland, England and Wales. The behavioural activation intervention, (BeatIt), lasts 12 sessions and was adapted from the Brief Behavioural Activation manual (Lejuez et al, 2011). BeatIt aims to work with the participant and their supporter to help them re-engage in meaningful and positive activities in keeping with their life goals and values, thereby improving their mood. The intervention also includes an explicit attempt to tackle emotional and organisational barriers to change. The guided self-help psycho-educational intervention (StepUp), has eight sessions based around four booklets produced by Melville et al. (2009). The booklets were developed for use with adults with intellectual disabilities and depression and cover i) the nature of depression, ii) sleep, iii) physical activity, and iv) problem solving. Crucially, both of the interventions were delivered to the participants with an intellectual disability alongside a support person in their lives, who was a family member, support worker or friend.

The trial found no difference in the outcomes for participants receiving the BeatIt or Step Up interventions at twelve months after baseline. However, both interventions were associated with positive change on the primary outcome of self-reported depressive symptoms. This change was found at the four month post intervention follow-up and maintained until the twelve month follow-up data collection (Jahoda et al, 2017). A full description of the trial interventions and findings are provided in the published protocol (Jahoda et al, 2015) and the main outcome paper (Jahoda et al, 2017).

The interview data presented in this paper is being reported in its own right, rather than as part of a wider process study, synthesizing different strands of work from the trial.

Method

Participants

A sample of 25 participants (8 male, 17 female), who had received either BeatIt (15) or StepUp (10), were interviewed. They were selected from 161 participants who had taken part in the RCT. Participants were purposively sampled, guided by matrices of participant circumstances and characteristics, within each of the three sites. This helped to ensure there was diversity in terms of living situation, location (England, Scotland or Wales), gender and

the nature of their support person who accompanied them to therapy (family or paid staff). Their ages ranged from 21 to 66 (Mean 37.7; SD 9.5) and their Wechsler Abbreviated Scale of Intelligence (WASI, Wechsler 1999) scores ranged from from 44 to 75 (Mean 58.5; SD 9.8). The participants' living situations varied with 15 living independently, 5 living in the family home, 4 living in a group home and 1 in supported accommodation. A breakdown of the participants' living situation and who their supporter was in therapy are shown in Table 1.

Interview

A semi-structured interview schedule was developed by members of the research team to explore the participants' experience of receiving therapy. The schedule was divided into four topics, with opening questions which could be followed up with further questions or prompts. The topics comprised of: 1) participants' expectations of therapy; 2) participants' view of the therapy sessions; 3) working relationships with therapist and supporter; and 4) perceived therapeutic changes and maintenance of change. The aim was to establish a dialogue with the participants, using the guide to ensure that key topics were covered whilst having the flexibility to follow-up other salient issues they raised.

Procedure

All participants agreed to be interviewed as part of initial consent provided when first agreeing to take part in the RCT (Jahoda et al., 2015). Those selected to be interviewed were then contacted again by the researchers prior to the interviews, to check that they were still willing to take part in the qualitative component of the study. All of those contacted were still willing to be interviewed.

The interviews took place within eight weeks of the participants completing therapy. The aim was to carry out the interviews within this time frame to ensure that they would still be able to recall their experience of taking part in therapy.

Participants were interviewed at a location of their choosing, which was either at home or a day centre they attended. The interviews were conducted by three different researchers, one each in Scotland, England and Wales. Interviews in one site were carried out by a researcher from another site, to avoid unblinding for the quantitative data collection. The interviews were audio-recorded using digital equipment and each recording was transcribed verbatim. The interviews were between 20-80 minutes in duration. Two participants declined to be audio recorded but extensive notes taken of the views they expressed were used for the purpose of the analysis.

Data analysis

The qualitative method used in this study was framework analysis, developed by Ritchie and Spencer (1994) for analyses in applied social policy research but now used more widely. One of the main features of framework analysis is the 'matrix output', where the framework for analysing the data is used to bring together all participants' responses with regard to each particular issue or topic being analysed. This allows for comparisons to be made across the sample and also within individual interviews, meaning that whilst comprehensive analyses of key categories arising across the entire dataset is possible, individual participants' views remain (Gale et al 2013).

A key aim of this qualitative component of the wider RCT was to increase our understanding of how each intervention operated as part of the RCT as a whole. The framework analysis allowed some specification of the dimensions of interest, whilst retaining the potential for emergent themes to revise or add to the framework. This structured approach to the analysis was also necessitated by the relatively large number of interviews which were carried out.

Once the interviews were transcribed, an initial framework, closely related to the topic guide, was developed. The framework was agreed on by the three investigators who conducted the interviews, an investigator responsible for merging coded interviews, and two investigators with expertise in qualitative research. The three investigators who conducted the interviews then coded two interview transcripts each, with the investigator responsible for merging these coded interviews into the agreed framework attempting to merge them and the additional two investigators also reading through the transcripts and the initial coding. At this point, the framework was modified to encompass categories which were not present in the original framework, through discussion with all the investigators involved. All the interview transcripts were then coded by the interviewing investigators and merged into the revised framework by the fourth investigator using NVivo 11 (QSR International, 2016). The final framework themes were agreed by all the investigators involved in the process of analysis.

Ethics approval

Ethical approval was granted by the West of Scotland Research Ethics Committee 3 as part of the wider study (Jahoda et al, 2015). The International Standard Randomised Controlled Trial Number (ISRCTN) reference number is ISRCTN 09753005.

Results

Table 2 summarises the 12 sub-categories that were distilled from the agreed framework for the analyses using the following six categories: Before therapy; The therapy process; Relationships in therapy; Ending and after therapy; The impact of therapy; Participants' views on therapy. The table provides the categorical data from the primary analyses of the participants' views, although it needs to be kept in mind that this is not a representative sample. The nature of the participants' views are described below, illustrated with quotes. Real names have been replaced with pseudonyms in the quotes.

Category 1: Before therapy

The first category concerned the participants' recall about what brought them into therapy. There were two sub-categories, what problems they felt that they had at the time and their views and expectations of therapy (see table 2).

Participants' problems: The two groups of participants brought broadly similar difficulties to therapy. Some participants said their problems related to feeling depressed or down, others described struggling with loneliness or a lack of confidence.

> 'Just to help me with my moods, particularly in the New Year, that's when I go down, first of New Year.' (BeatIt; Female; Participant 80)
>
> 'Hopefully it would be helpful. To get me out a bit more and less shy going into shops. Being less shy. Being less nervous as well.' (StepUp; Female; Participant 289)

Issues with anxiety and anger were also raised, highlighting that problems with low mood or depression were rarely talked about in isolation from the other personal or interpersonal problems people faced. Life events also came to the fore. Some participants felt their main difficulties related to bereavement and loss, and others identified bullying or victimisation as the cause of their distress.

> 'That's what made me so depressed at one time, because I kept being bullied at work and that's why I didn't go in (to work) for a couple of days… Mum thought it was great joining the programme because I was feeling down at the time.' (StepUp; Female; Participant 295)

Participants' feelings / expectations: The two groups' expectations and feelings about starting therapy were similar, with some participants saying that they had no worries. Others said that they had optimism about therapy from the outset. They expressed hope that it would help them achieve their life goals and four participants hoped that therapy would help to lift their low mood or depression.

> ‘I thought it (the therapy) was a good idea because at the time I was really, really down… I wanted my life to be better to what it was before. Happier.’ (StepUp; Female; Participant 295)

Perhaps unsurprisingly, a number of participants felt nervous or uncertain about starting therapy.

> ‘I don’t (sic) know what to expect, I was surprised in a way. …It was scary first time meeting the therapist and then, yea, getting to know each other.’ (BeatIt; Female; Participant 96)

Category 2: The therapy process

This category concerned the participants’ experiences of the therapy process. The three subcategories concerned what the participants identified as being the important aspects of therapy, their recall of the therapeutic materials and views of homework tasks, even though it was only the BeatIt participants who were meant to carry out homework tasks (see table 2).

What was important: The two groups identified different process issues as being important, in line with the differences between the interventions. Whereas BeatIt participants highlighted being listened to and planning activities or completing relevant paperwork, StepUp participants focussed on going through the booklets.

One woman recalled a therapy task used to find out people’s past, present and desired activities:

> ‘I remember the cards, the things that you say what you do day to day. I had the two boxes and the cards rather than the pictures and things like that. So that was quite fun. And drawings and diaries as well.’ (BeatIt; Female; Participant 290)

The descriptions of going through the booklets given by the StepUp participants revealed a good recall of both the content and purpose of the different booklets:

> ‘One week we did one book about sleeping and then we went through all the books we were given. We were given lots of books to read through. …The other ones were to do with things like getting up and moving, things like dancing, go to groups, socialising, getting out and about, doing different things, getting in the community, doing things you don’t normally do.’ (StepUp; Female; Participant 211)

Materials: The same pattern emerged for the therapy materials, with BeatIt participants talking about the materials used in sessions to make activities more accessible, along with the activity diaries, activity planning sheets, and formulation booklets which provided a shared rationale for the therapist’s work with the participant and their supporter. The focus of

StepUp participants was again on the use of the booklets, although they did make mention of the mood ratings routinely collected in sessions.

The way BeatIt participants described the use of the materials showed a clear grasp of their purpose. One man explained his thinking behind his choice of three key activities for the planning sheet:

> '…because a lot of this is to do with my anxiety and depression, to try and beat, combat the feelings and the mood and mainly anxiety and depression. And so I just thought, three things that I could possibly get into, one like going to the gym because it makes you physical and mental feel better.' (BeatIt; Male; Participant 199)

What came through from StepUp participants' descriptions of using the booklets was the way they were interpreted to make them personally salient. A section about budgeting in one of the booklets resonated with one of the participants:

> 'The booklet were very interesting. Then I realised what I've been doing wrong all these years in a way that I feel you know, like the financial side was the main one really, I actually got to grips with because I would just spend my money willy nilly. I know that's not the right way to do and then I found myself like hang on, I knew it was wrong.' (StepUp; Male; Participant 252)

However, a few StepUp and BeatIt participants were concerned that they lacked the necessary literacy skills for using the various therapy forms and booklets. Some StepUp participants also felt that the booklets could have been better presented. One participant had particular difficulties with the Problem Solving booklet:

> 'I was a bit muddled up with the problems solving one (booklet).' (StepUp; Female; Participant 272)

Activities between sessions: The BeatIt participants talked about becoming more active or carrying out planned tasks between sessions, a key focus of the intervention. The process of recording what they did was also important to many of them. One participant talked about following through the plans he had made in sessions:

> 'And then I started taking meself off instead of going to the pub because Susan helped me get a pass from my doctor so I get free travel and all that. …Days out, going to different places and just having a wander round and some dinner and coming back. …That's when I used to see them (diaries) and write it down. …I used to love those little booklet (diaries) things.' (BeatIt; Male; Participant 182)

The absence of homework tasks for the StepUp group was reflected in the finding that few of these participants mentioned going through the booklets with their supporter between

sessions. However, some StepUp participants did mention using coping strategies discussed in their sessions. It is understandable that a number of therapists apparently tried to support participants to put into practice ideas discussed in sessions, even thought the trial protocol had stated that the StepUp arm should adopt a narrow psycho-educational approach. For example, a set of strategies had been put in place by the therapist and supporter for one participant who became distressed by what he thought other people were saying:

> 'My tasks were, if I misheard something or was worried about something, go through it myself, self-help, then it was like read things (notes written for him) on the wall, then he suggested writing things down and passing it onto (support workers).' (StepUp; Female; Participant 209)

Category 3: Relationships in therapy

Human relationships were central to the therapeutic experience of both sets of participants (see table 2). The first sub-category concerned the participants' relationships with the therapist, the second category was about the participants' views about being accompanied to sessions by a supporter, which most found to be helpful. The third sub-category was about working alongside both a therapist and supporter in sessions, which most felt was carried out in a spirit of collaboration.

Relationships with the therapist: The overwhelming view from both sets of participants was that they enjoyed close and trusting relationships with therapists and this was a key part of therapy. Some participants also expressed a view that it was easier to talk to someone new. One BeatIt participant described her relationship with her therapist as follows:

> 'She's been good for me definitely, definitely. We did things and talk about things that I would never talk about. …Helpful that they're an outside person.' (BeatIt; Female; Participant 182)

Similar sentiments were expressed by a StepUp participant:

> 'Everything she (therapist) did she explained, so it wasn't so bad. I got into it, like you know. Because the therapist let me talk about what I wanted to talk about you know, I felt more comfortable being that way.' (StepUp; Male; Participant 252)

There was also a sense with BeatIt participants that their relationships with therapists were key to making changes in their lives, facing their fears and dealing with painful issues they had avoided. One woman talked about being persuaded by the therapist to get help with longstanding problems which had left her torn between chronic pain and her fear of visiting medical professionals.

> It was useful to talk about my problems like the depression side of it, that's what we used to talk about. And she'd say like she used to talk to me about… the dentist and then the doctors. I don't like going to the doctor and I would just stay in the house and I used to have a fear about going to the dentist, having to go. I would just sit there and say 'no, I'm too scared to go to the dentist, I don't want to go, I'm scared, I've got a fear'. And then Jane pushed me to go to the dentist, so I went, so I was fine about it, and then the doctors. I said 'I don't want to go and see them in case anything happens'. And after that she pushed me to go to that as well, so I think I done real well at it. (BeatIt; Female; Participant 97)

Relationships with the supporter in therapy: Most participants from both groups reported enjoying good relationships with their supporters in therapy sessions, believing that having someone they knew in sessions helped to overcome their anxieties about meeting with therapists. Supporters offered both practical and moral support:

> 'I found it good my mum being there with me, to support me all the way through. …I didn't want to be on my own sitting there.' (BeatIt; Female; Participant 200)
>
> 'I would probably have been a bit more shy and nervous if mum wasn't there.' (StepUp; Male; Participant 289)

However, a few participants reported they did not enjoy good relationships with their supporters or would have preferred to meet the therapist on their own. This was strongly expressed by one woman:

> 'When my support worker was there I didn't really like that bit of it to tell the truth, I have to be honest with that. 'Cos I had to sort of watch what I was saying as maybe stuff that I want to talk about but my support worker was there all the time, it was like she took control in a way about how she thinks I am. But when you know how you're feeling, you know that's how you're feeling. …I am an adult do you know what I mean?' (BeatIt; Female; Participant 075)

Working with the supporter and therapist: Participants who expressed a view about working alongside both therapists and supporters were mostly positive and viewed therapy sessions as a 'joint' venture. Several participants thought that the supporter was also benefiting from the therapy, giving a sense that they felt on an equal footing with them in sessions. One of the StepUp participants talked about a shared difficulty with sleep:

> 'It was good because we got to understand each other a bit better (participant and supporter) and where we were coming from. She struggled with sleep as well so she

learned a lot of things as well, so it wasn't just me.' (StepUp; Female; Participant 211)

The supporter was often seen as playing a vital role in scaffolding the participant's involvement in the therapy sessions. One BeatIt participant (200) described how having her aunt at the sessions helped to promote the flow in sessions

'It helped having a supporter there because I was stuck. My auntie come up with some ideas. It was good, when I was stuck she came out with ideas.' (BeatIt; Female; Participant 200)

However, a few participants did not find the supporter's presence helpful, with one individual making it clear that she found the presence of the supporter demeaning. The woman quoted above (075) who objected to the presence of her support worker at BeatIt sessions said, 'it put a spanner in the works'.

Category 4: Ending and after therapy

The first of the two sub-categories was about the participant's feelings about finishing therapy and ending their relationship with the therapist. The second category was about maintaining or building on the progress made. Some continued to use the therapy materials or strategies that they had learning in sessions, while others said that they could still recall the value of what they had learned (see table 2).

Feelings about ending therapy: Both sets of participants felt the interventions had been too short and they wanted continuing help. Several participants asked if they could start the therapy again.

'I thought it would be much more than 12 weeks, whatever it was. I don't want something forever but just until I feel right and ready to let go kind of thing. I thought it would be much more than that.' (BeatIt; Female; Participant 75)

'I would have liked it (therapy) to go on for – well the rest of my life actually. But I know that won't happen like. You know the therapist did say it's only eight sessions and that's it you know.' (StepUp; Male; Participant 252)

Others felt a real sense of loss that their relationship with the therapist had come to an end. One of the BeatIt participants talked about her wish for a follow-up visit from the therapist:

'I said to mum, do you think (the therapist) will come to the house? Just do a wee visit to see how I'm getting on, not to stay… So she said, I don't think she'll come back.' (BeatIt; Female; Participant 97)

A StepUp participant talked about struggling with the end of the therapeutic relationship:

> ‘Aye, I think we built a relationship, she was actually alright, she was nice. But again, I will never see her again. I don’t see how it has to be that way but it’s what they do. I don’t mean like glue or have them in my network or contact, that I could meet the therapist and see how she is going. …I get on better with (therapist than with) any of the numpties out on the street there and they (therapist) want to be my friend but can’t be your friend because that isn’t allowed and that’s the rules.’ (StepUp; Male; Participant 64)

However, a few participants reluctantly said they felt ready to finish therapy as they were feeling better.

> ‘ I was quite sad that it finished because I could have done with some more sessions of therapy to be honest but sadly these things have to come to an end. So you have to make the most of what you’ve got, don’t you? (StepUp; Female; Participant 211)

Maintaining change: Several BeatIt and StepUp participants said they had kept using the ideas and materials from therapy. BeatIt participants made particular mention of the formulation booklets and maintaining the activities they had started. Many of the BeatIt participants said they found the diaries and planning sheets particularly useful and had asked for copies to use after therapy had finished or used their own versions. One participant described how keeping her own diary of activities had helped her to maintain her new routines:

> ‘ No I don’t use the diaries any more. I’ve got my own diary in my bag. I usually write what I do and then if mum and dad what they do… but I think it’s fun to.’ (BeatIt; Female; Participant 97)

While some talked about looking through formulation booklets with supporters, others felt it was up to them to maintain change. One participant said:

> ‘I don’t know, I think I helped myself in a way, ‘cos obviously I got to do things myself. No one else will do them for me.’ (BeatIt; Female; Participant 290)

StepUp participants also talked about continuing to look at the booklets, emphasising how this reminded them of helpful strategies they had discussed in sessions. One participant said he found the ‘activity booklet’ most helpful when he was feeling down:

> ‘My favourite one is the activity. If I do feel down I can drag myself out and then just go somewhere and that. …Yea, go for a long walk or maybe have a bath or just go to (nearby town) or something for a day.’ (StepUp; Female; Participant 209)

Even those who had stopped using the booklets still believed they would be helpful. One woman said that she would 'use the books in the future':

> 'If I've got a problem I know what I can do now. I've kept them (the booklets), I've not thrown them out.' (StepUp; Female; Participant 211)

Category 5: Impact of therapy

This category concerned the participants' views about how therapy had benefited them personally. There was a strong sense that the participants felt that therapy had had a positive impact on their sense of self and self-efficacy (see table 2).

Impact on the person: While more BeatIt participants talked about therapeutic outcomes, the two groups of participants expressed similar views. Being more active, having better mood and better relationships were directly attributed to therapy, with a particular emphasis on improved relationships with the support person.

One BeatIt participant felt his mood had lifted as a result of getting on top of his domestic affairs:

> 'But since I've been to therapy it's totally different because I've started cleaning up my flat, cleaning myself up and going shopping. I have come on leaps and bounds and it's all because of this. I don't think I'd have got through it otherwise. …If it wasn't for this and a couple of other friends, I think I'd be dead by now.' (BeatIt; Male; Participant 182)

Improved relationships with supporters reflected participants' views that supporters understood them better. As one BeatIt participant explained:

> 'I think (supporter) would say it's (therapy) made a difference, she knows me quite well. She knows me better since doing the therapy.' (BeatIt; Female; Participant 279)

Participants also described the impact on themselves in terms of boosting their self-esteem and self-confidence. One StepUp participant felt the therapy had helped her become less 'shy' and 'nervous' and more 'happy and 'confident'.

A few StepUp participants felt that the therapy had helped to end bullying and victimisation. One of them believed that the therapy had helped to change how other people treated her:

> 'I wanted it so that I didn't have to be spoken to like a child and that people understood me and not like treated me differently. The therapy definitely did that.' (StepUp; Female; Participant 272)

It was unclear whether this perceived change in bullying and victimization was due to greater self-confidence on the part of the participants about tackling discrimination or whether a

change in their own behavior or self-confidence might have resulted in others treating them with greater respect.

Category 6: Participants' views on the therapy overall

Ideas for improving therapy: BeatIt participants had few specific comments about how the therapy could be improved, other than general concerns about the need for literacy skills to complete some of the materials independently. In addition, StepUp participants had suggestions for additional topics to be covered by the booklets, including how to deal with mood swings. Suggestions were also made about improving the pictures used in the books and the presentation of the materials, including the need for larger text. Several participants also felt that their sessions were rushed and wanted to have more time to go through the booklets.

One of the StepUp participants was more critical and found the format of the booklets demeaning:

> 'See the pictures, that is something like when I used to go to school. I don't like that I am not a child and I just mean that I don't need to draw daft pictures of wee people. …Just because I have problems I don't need daft wee pictures with loads of colours to make me feel, I don't need that.' (StepUp; Male; Participant 64)

Discussion

The study found that most participants welcomed the opportunity to receive a therapeutic intervention and they were clear that they were receiving help because of low mood and depression. Interestingly, they did not just view their depression as an internal problem but linked it to life events and challenges in their lives such as loneliness. In common with past findings relating to CBT and behavioural activation (Pert et al, 2013; MacMahon et al, 2015; Finning et al, 2017), the participants identified specific therapeutic exercises and materials that they had found helpful and engaging but also valued the therapeutic relationship. Therefore, perhaps it was unsurprising that the main criticism of the interventions was that they were disappointingly short.

Both sets of participants demonstrated a good grasp of the therapies that they received and described how the therapeutic materials and activities (e.g. scheduled events for the BeatIt participants, and booklets for the StepUp participants) were made relevant to their lives. In previous research concerning people with intellectual disabilities' experience of psychological interventions the non-specific aspects of psychological interventions, like being listened to and developing a rapport with the therapist, have been considered separately from therapeutic techniques (Pert et al, 2013). However, definitions of therapeutic alliance are concerned not merely with the therapeutic bond but also with working towards shared goals (Hovath et al, 2011). Perhaps the strength of the therapeutic relationship depends, at least in part, upon having therapeutic materials and techniques that can be made personally salient. This may highlight the importance of ensuring the content of adapted approaches for people with an intellectual disability are not merely more accessible but also relevant to their lives and experience.

One of the main adaptations made to the BeatIt and StepUp interventions was the delivery of the interventions to both the person with an intellectual disability and a supporter. Consistent with past findings about the positive impact of including supporters in therapy sessions (Rose et al, 2005), most participants from both groups found the supporters' presence helpful. Not only did the participants believe that the supporter was able to facilitate their engagement in therapy but some expressed the view that working alongside their support person in sessions had helped to build mutual understanding and strengthen their relationships. However, a small minority found the presence of the supporter both unnecessary and degrading. These participants wanted to have a private confiding relationship with the therapist and their views are consistent with participants from previous studies who sought a one-to-one therapeutic relationship (Pert et al 2013).

Even though participants from both groups reported positive changes in their lives, which they saw as a consequence of taking part in therapy, many of them appeared unhappy at the time limited nature of therapy. Some appeared to be distressed by what they viewed as the abrupt end of the relationship they had built with the therapist, whilst others wanted continuing support or therapeutic help over the longer-term. These findings suggested a gap between therapeutic intentions and the kind of help the participants wanted. Building rapport or a bond with clients is thought to be a core task of the therapist. However, some participants seemed to find it difficult to understand the boundaries of the therapeutic relationship and felt a sense of personal loss when therapy ended. This may not be surprising, given that many people with an intellectual disability have few confiding relationships (Jahoda and Pownall, 2015; Lippold and Burns, 2009).

It may be that the participants' wish for longer-term relationships with therapists was simply due to the limited number of therapy sessions delivered as part of this brief behavioural activation intervention (Lejeuz et al, 2011). The number of sessions that the intention to treat participants received in the COBRA trial of Behavioural Activation were 16 (Richards et al 2016), and the average number of sessions the BeatIt participants attended were 10 (Jahoda et al, 2017). However, anxiety about losing therapeutic help was also raised as a concern in a previous study where participants were receiving longer-term Cognitive Behavioural Therapy interventions (Pert et al, 2013), and this may reflect a broader wish for a continuing supportive relationship. A number of adaptations were made to the Brief Behavioural Activation try and ensure that there was sufficient meaningful engagement for individuals with intellectual disabilities. Most sessions lasted for approximately two hours and a significant other accompanied the participants to therapy sessions, to help them carry out homework tasks and generalise therapeutic gains. Even then, it was not anticipated that twelve sessions would be sufficient and the final sessions involved developing a booklet

along with the participant and their significant other, to help them sustain and build on progress made in therapy. In future, it may be worth including follow-up sessions to make the end of therapy less abrupt and to increase therapeutic input.

Other participants very much understood and valued the fact that the therapist was not a family member, friend, or one of their usual support workers. Once again, their wish for a continuing supportive relationship with the therapist may have reflected the fact that they have few confiding, non-judgmental relationships in their lives. A lack of confidence about maintaining the changes they had achieved in the course of the intervention may also have made some participants more anxious about losing therapeutic support (Pert et al, 2013). Whatever the interpretation, it is likely that the participants made sense of therapy in the context of their wider lives and circumstances, and their previous experience of professional relationships. It should also be noted that there were participants who demonstrated considerable agency and had continued to use the therapeutic materials and resources once the interventions had finished.

In terms of therapeutic outcomes, the participants highlighted changes that they had made to their lives and relationships, as well as changes to their mood and confidence. This contrasted with the findings from the quantitative measures used in the trial (Jahoda et al, 2017), which failed to detect any change in activity. This difference might have simply been due to a bias in the sample of participants who were interviewed. However, the disparity between the quantitative and qualitative findings may also reflect a limitation with the self-report measures of activity, which may not be sensitive to small changes in activity or the salience that individuals attach to such changes.

The participants made a number of specific suggestions about how the BeatIt and StepUp interventions could be improved. In terms of content, participants put forward ideas about making materials such as diaries, activity scheduling sheets and the guided self-help

booklets more accessible or engaging, with larger text and different pictures. Yet any changes would have to be made with care as some participants were also sensitive about materials appearing too childlike or demeaning. A solution could be to offer participants a choice of formats. In terms of therapy process, there were particular constraints when delivering interventions as part of a clinical trial. These protocols could be made more flexible and person-centred in routine practice.

Implications

Many of the issues discussed above have a broader relevance to the delivery of psychological interventions to people with intellectual disabilities. The importance of empathic therapeutic relationships remains an under researched topic with this population (Pert et al, 2013). In particular, it would be helpful to develop a better understanding of how empathic relationships can help to facilitate change. Supporters also played an important role for many of the participants, helping to reduce their anxiety when starting therapy. While the individuals, their support person and therapist did not exactly constitute a group, there was an opportunity to develop mutual support and understanding that was akin to that described in MacMahon et al (2015) et al's study. If an aim of psychological interventions is to promote change that extends beyond the therapy room then it would be interesting to investigate the use of a mixed model of therapy with individuals who have intellectual disabilities and their supporters. Individuals could enjoy a confiding therapeutic relationship alone with their therapist whilst carrying out other therapeutic work involving a support person, to help achieve real life change. Finally, it appears that endings in time-limited manualised therapies may be particularly problematic when working with individuals and intellectual disabilities and this is an area that needs further consideration (Jahoda, Pert & Kroese, 2017). Building in follow-up or booster sessions may help overcome some of the participants' concerns about finishing therapy. Of course, if the intervention were to be delivered by a practitioner such as

a community nurse who has an ongoing relationship with the person, then the therapy could finish without the relationship ending.

Limitations and future research

A limitation of this study is that the qualitative analysis asked participants to reflect on a therapeutic process they had finished some weeks before. Another potential drawback was that twice as many female participants were interviewed and different issues may have been to the fore if there had been a better gender balance. Caution is needed when considering the broader implications of these findings for people with intellectual disabilities receiving psychological interventions because this was a qualitative study and it is not a representative sample. Furthermore, the study used a Framework Analysis approach (Richie and Spencer, 1994), providing a less in depth insight into the participants' experience of therapy that might have been obtained from a method like Interpretative Phenomenological Analysis (Smith, 2011). In future research, it would be interesting to explore how participants' views about aspects of therapy, such as the involvement of support persons, evolve as therapy progresses. While the study showed that the participants' experiences of therapy were largely positive it was less clear how easy it had been for them to sustain or build on the work done in sessions once the interventions had finished. Investigating the barriers and factors that help individuals to generalise and sustain the changes they make in therapy is a vital area for future research.

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Table 1: Participant Living Situations and Therapy Support

Participant characteristics	**Description**			
	Independently	Family home	Group home	Supported living
Living situation	15	5	4	1
	Paid support worker	Family member	partner/friend	Health professional
Supporter relationship	15	7	1	2
	Scotland	England	Wales	
Location	7	8	10	

Table 2: Number of participants mentioning themes and sub-themes by intervention type

Theme/sub-theme	Beat It (N=15)	Step Up (N=10)
Theme 1: Before therapy		
Sub-theme: Participants' problems		
Depressed/down	3	2
Loss/ bereavement	2	0
Loneliness / confidence	2	2
Bullying / victimisation	1	1
Anger/ anxiety	2	1
Sub-theme: Participants' feelings and expectations		
No worries	5	0
Nervous / uncertainty	2	5
Help achieve life goals	2	1
Help depression / mood	3	1
Theme 2: The therapy process		
Sub-theme: What was important		
Talking and being listened to (session exercises)	6	
Ideas for me – planning a way forward	9	
Grasping the paperwork (diaries, mood and planning)	6	
Confidence building	2	
Reading the books & understanding more		4
Relating the books to me		4
Sub-theme: Materials		
Diaries useful (although support needed)	12	
Activity task pictures (helpful)	4	
Formulation booklets (person centred)	6	
Activity sheets (planning and shared focus)	5	
Individual materials to tackle barriers to progress	2	
Problems remembering to use materials	3	
Felt lacking necessary literacy skills	3	
Booklets useful (when accessible)		9
Booklets inaccessible or confusing		2
Sub-theme: Activities between sessions		
Diaries (need for support)	2	
Getting out - a more active life	6	
Taking control – doing more	6	
Reading through books with supporter		2
Using coping strategies discussed in sessions		2
Theme 3: Relationships in therapy		
Sub-theme: Relationship with the therapist in therapy		
Talk openly and trust	8	2
Developed a close relationship	5	5

Sub-theme: Relationship with the supporter in therapy		
Helpful / put me at ease	6	5
Key to achieving change	2	3
Unhelpful / challenging	2	1
Sub-theme: Working with supporter and therapist		
Scaffolded by supporter	5	4
Joint working	6	3
Supporter unhelpful / unnecessary	1	2
Theme 4: Ending and after therapy		
Sub-theme: Feelings about ending therapy		
Too short / can I do it again	4	4
Sad to end relationship with therapist	4	2
Feel a lot better / reluctant acceptance	2	1
Maintaining change		
Using formulation booklets	6	
Keeping activities going	5	
Still completing diary sheets	3	
Still working towards goals	2	
Using books and strategies		4
Believe books still helpful but not looked at them		3
Theme 5: The impact of therapy		
Sub-theme: Impact on the person		
More active lives	9	4
Mood improved	4	3
Better relationships	3	3
More positive sense of self	11	5
More independent	3	
Bullying / victimisation stopped		2
Theme 6: Participants' views on the therapy		
Sub-theme: Ideas for improving the therapy		
Make aspects of therapy less complicated	2	1
More books (family and depression, mood swings)	0	2
Better pictures - improve presentation of books	0	3
More time (for sessions and number of sessions)	0	2